

What we think about unpaid carer support

POSITION STATEMENT. LAST UPDATED: *April 2025*

Key messages

Every unpaid carer has a legal right to a carer's assessment. Yet even if they do access one, support provision does not necessarily change. The Care Quality Commission (CQC), which assesses local authority social care functions, has found significant variability in performance. It is vital that local authorities seek to identify carers in their area, ensure each carer accesses an assessment of their needs, and that those they support receive high-quality, consistent care.

Unpaid carers enable people with MND to live well by providing vital care and support, but they need support themselves to continue caring. Every carer should have equitable access to respite and replacement care from a skilled social care workforce.

Unpaid MND carers save local health and social care systems approximately £217m a year by providing care that would have otherwise been met by formal care. It is necessary and appropriate that carers do not face financial difficulty while caring. The rate of Carer's Allowance should be immediately uplifted to a level that reflects the value unpaid carers provide, and its strict eligibility requirements should be removed to ensure that all carers are eligible for financial support.

Background

An unpaid carer is anyone who cares, unpaid, for a friend or family member who, due to illness, disability, a mental health problem or addiction, cannot cope without their support.¹ In 2024, the number of unpaid carers was estimated to be 5.8 million, or every one in nine adults, in the UK.²

High care needs associated with MND often mean carers spend a significant amount of time caring for their loved ones. Over half (52%) of MND carers report spending over 75 hours a

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week providing unpaid care to their loved ones, and eight in ten (79%) spend over an average working week (35 hours) providing care.³

Also, the complexity of symptoms means MND carers often provide a wide range of care for their loved ones. For instance, 83% and 82% of MND carers reported providing higher level care such as personal care and physical help, respectively, as well as lighter touch care, such as giving emotional support (92%), helping with paperwork and financial matters (88%) and keeping their loved ones company (88%).⁴

In 2023, the value of unpaid care was estimated at £445m per day.⁵ Unpaid carer labour saves costs from what might have otherwise been met by formal, paid care, such as local authority-commissioned home care. We estimate that carers of people living with MND in the UK save the health and social care systems £217m a year, equivalent to £40,000 per carer, per year.

Often, the physical and mental exhaustion of caring means that many carers struggle to continue to provide support whilst managing high levels of fatigue and stress.⁶ This can result in carers feeling unable to manage in their caring role. Two-thirds (66%) of MND carers report being mentally exhausted from caring, as well as stressed (75%) and physically exhausted (64%).⁷ The MND Carer Triple Burden report also found that 81% of carers used personal savings or retirement funds to meet caring costs, and 22% had gone into debt, highlighting the urgent need for financial and emotional support mechanisms to sustain unpaid care.⁸ It is therefore essential that unpaid carers are fully supported to continue in their caring role.

The challenge

Carers' assessments

A carer's assessment is an assessment of carer needs and seeks to understand what carers might need to continue in their caring role. An assessment usually covers topics such as carers' mental and physical health, their ability and willingness to care, and their relationships with

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others. The Care Act 2014 in England, the Carers and Direct Payments Act 2002 in Northern Ireland, and the Social Services and Wellbeing Act 2014 in Wales prescribes carers a right to a carer's assessment.

Awareness of, and access to, carers' assessments

Despite a right to a carer's assessment enshrined in law, not all carers are aware of them. In 2021, four in ten (40%) carers of people with MND stated they were unaware of their right to an assessment.⁹ It's essential that local authorities in England and Wales and Health and Social Care Trusts in Northern Ireland improve the awareness of carers' assessments to eligible carers. This can be done by working with health services to improve early identification to ensure carers are aware of their right to an assessment.

Moreover, just a quarter (25%) of MND carers state they have had or are in the process of having a carer's assessment.¹⁰ This is concerning given the significant mental, physical, and emotional burden of caring for someone with MND. Two-thirds (66%) of MND carers state they have had 'no' or 'not enough' support in relation to their caring role.¹¹ It is unacceptable that a high number of current carers have not received a carer's assessment, leaving them without access to vital support.

The length of time people wait for carers' assessments is also concerning. Data from Freedom of Information (FOI) requests show that between 2018 and 2023, carers have been waiting, on average, between 42 and 49 days for an assessment. There is also a postcode lottery for how quickly people will receive an assessment, with some receiving it over a year later, depending on their location. The rapid and progressive nature of MND often results in a quickly increasing burden on carers. Seamless and timely access to assessments is therefore vital to ensure carers do not go without support in their caring role. However, 82% of local authorities do not have fast-track routes to assessment in place.¹²

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Implementing formal fast-track processes for the delivery of carers' assessments is vital to ensure that carers receive the support they need quickly, ultimately improving the quality of care for individuals with MND and enhancing the well-being of their carers.

Quality of carers' assessments

Following a carer's assessment, local authorities in England and Wales and Health and Social Care Trusts in Northern Ireland will decide whether a carer is eligible for support. If they are, a care and support plan will be written, detailing the necessary support provision for the carer.¹³

The types of support that can be offered include financial assistance (direct and part-direct payments, as well as personal health budgets), commissioned support (such as homecare), information and signposting, and respite care.¹⁴

However, carers' assessments are not working as they should. Almost one-third (30%) of MND carers report receiving no direct support following an assessment.¹⁵ This is unlikely to be appropriate given the high burden of caring placed on carers of people living with MND. Data from 2021 shows that over half (52%) of MND carers experienced physical strain because of caring, 15% developed their health condition, and a quarter (24%) stated that providing care had made an existing condition worse.¹⁶

Carers have previously reported frustration with assessors for misunderstanding the complexities of caring for someone with MND.¹⁷ It is likely that a poor-quality assessment will not facilitate access to the proper support, and therefore, carers will be left with unmet needs.

Every unpaid carer has a legal right to a carer's assessment, yet many face delays or receive limited support even after one is completed. The Care Quality Commission's (CQC) 2023–2024 report highlights persistent inconsistencies in the quality and accessibility of these assessments, with systemic issues such as outdated inspections and inadequate follow-up care. As the CQC expands its oversight under the Health and Care Act 2014, it is crucial that local

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authorities not only adopt best practices but also implement them effectively to ensure carers receive the support they are entitled to.¹⁸

Respite care

Caring for someone with MND can be challenging and can result in negative outcomes for carers emotionally, mentally, and physically. For example, 41% of carers report feeling depressed because of caring, as well as mentally (66%) and physically (64%) exhausted.¹⁹ Isolation, loneliness, and despair are common experiences for unpaid carers of people living with MND.²⁰

Respite care offers essential breaks for caregivers to engage in tasks or activities that have been overlooked due to the demands of caregiving, such as household chores or attending medical appointments.²¹ Respite care can include day care provision, short breaks and replacement care and is a vital support source for carers. Respite care is particularly important for MND carers; 85% report feeling tired as a direct result of their caring responsibilities, as well as feeling depressed (51%) and having disturbed sleep (73%).²² Sixty-one per cent of MND carers report that they are either neglecting themselves or unable to look after themselves well enough because of the time commitments of their caring responsibilities. Additionally, in 2024, 36% of MND carers had left full-time work, and 21% had reduced their hours, due to the unavailability and inaccessibility of respite and replacement care.²³

However, not all carers access respite care. Following a carer's assessment, only one in ten (13%) carers of people with MND received regular planned breaks such as respite or replacement care.²⁴ While it is not possible to extrapolate whether this figure is reasonable, workforce shortages in social care are likely to contribute to a lack of access.²⁵

Data from the first three months of 2024 (January to March) indicate that 160,875 hours of homecare could not be delivered in England due to staffing capacity issues.²⁶ Whilst it

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represents a 53% decrease compared to the same period in 2023, the Homecare Association reported in 2024 that almost 48% of home care providers were still unable to meet the demand, highlighting a significant gap in service provision.²⁷

Not only do workforce shortages affect carers' ability to access respite care, but also the skill of the workforce. Unpaid carers of people with MND have reported that local respite services did not provide access to care staff with the skills and experience required to support people with complex needs associated with MND.²⁸

An impact of poor respite care provision for unpaid carers of MND is carer breakdown, which occurs when carers are burnt out from their caring responsibilities and experience a lack of support. In 2023/24, 88% of Directors of Adult Social Services reported seeing unpaid carers come forward to their local authority with increasing levels of need, and for the second year in a row, Directors ranked burnout as the number one contributing factor to increases in carer breakdown over the past year.²⁹

Similarly, in 2023 over two-thirds of Directors (68%) reported an increase in referrals relating to carer breakdown, up from 65% in 2021/22 and around a third (34%) reported that their council has a reduced ability to fully meet the needs of unpaid carers in their local area.³⁰

Additional investment is needed nationally to ensure that carers, who save local health and social care systems significant costs through their caring responsibilities, can access effective respite services to manage their own health and wellbeing.

Financial impact of caring

Many carers of people with MND face financial hardship because of their caring role; 47% of unpaid carers report worrying about money, and almost half (49%) report that caring had caused them financial difficulty.³¹ According to the MND Triple Burden report, 91% of

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households impacted by MND were financially worse off than the year before, and 64% of carers had spent more than £2,000 in the past 12 months due to their caring responsibilities.³²

A large driver of this financial difficulty is the extra cost associated with living with MND. On average, people living with MND and their families incur an additional £14,500 a year to meet the costs of the disease, with many households spending much more.³³ The recent cost-of-living crisis has further exacerbated financial worries for households affected by MND. In our 2023 survey, we found nine in ten (91%) households were financially worse off than 12 months ago, and half (51%) struggled to afford basic living essentials, such as food, home heating and essentials.³⁴

Moreover, assistive equipment used by people living with MND is essential to keep them safe and independent, yet people with MND and their families can spend up to £600 a year using and maintaining these pieces of equipment, on top of other household energy costs.³⁵ However, those managing more advanced stages of the condition can spend up to £10,000 a year on electricity costs alone.³⁶

Carers are entitled to a Carer's Allowance if the person they care for is in receipt of a disability-related benefit such as Personal Independence Payment or Attendance Allowance.³⁷ As of April 2025, the Carer's Allowance rate amounts to £83.30 a week. Those whose earnings exceed £196 a week after tax, National Insurance, and expenses do not qualify for Carer's Allowance. If someone shares caring responsibilities with another, then only one person is entitled to Carer's Allowance.

Carers of people living with MND have previously reported frustration with the strict eligibility requirements of Carer's Allowance, as well as calling the adequacy of payments into question. It is therefore no surprise that just one in ten (10%) carers of people living with MND report that the welfare benefits they receive meet their needs, and 94% of respondents believe the

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current Carer's Allowance (£81.90 per week) is insufficient to meet their needs.³⁸ These inadequacies are compounded by the inflexibility of the current Carer's Allowance framework. According to our research, many carers feel penalised for attempting to work even modest hours, and 58% of carers say current benefits do not compensate for lost income from employment.³⁹

Assuming there are 5,000 unpaid carers of people with MND, our analysis shows that they save local authorities in the UK £217m year, equivalent to £40,000 per carer per year, or £834 per carer per week by providing care that would have otherwise been met by formal care. This is 10 times greater than what a carer would receive through Carer's Allowance per week. Financial support by the UK Government does not reflect the support needed or the invaluable contribution carers make to the health and social care system.

While it is positive that the government has increased the earning limit for Carer's Allowance from £151 to £196 per week, the immense impact of MND means that many caregivers must abandon work entirely, rendering the earnings limit irrelevant.⁴⁰ Despite needing to provide at least 35 hours – a typical working week – of care to be eligible for Carer's Allowance, the benefit is set at a lower financial rate than other work replacement benefits, and it remains the lowest benefit of its kind.

The Government should ensure that the level of Carer's Allowance reflects the value that unpaid carers provide. It should also ensure that as many carers as possible are eligible by addressing the strict eligibility requirements of Carer's Allowance. This includes revising the earnings threshold and reducing the 35-hour minimum threshold. It may also involve removing the limited eligibility rules if a person is cared for by more than one person, which does not accurately reflect the present-day nature of caring in different family circumstances, or account for alternative family structures.

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What changes do we want to see?

From Government

- The Government should deliver new, targeted investment to fund regular respite breaks for carers and support improved physical and mental health. This might include the Carers Week Coalition and Carers UK call for £1.5bn of ringfenced funding to support carers' respite in England, with commensurate funding for devolved nations.⁴¹
- The Government should review the level of Carer's Allowance to ensure that it better reflects the value provided by unpaid carers. Its strict eligibility requirements should also be addressed, such as removing the earning threshold, reducing the minimum time-spent-caring condition, and removing limited eligibility rules for individuals cared for by more than one person and for carers over State Pension age.

From local authorities

- Local authorities in England and Wales, and Health and Social Care Trusts in Northern Ireland, should prioritise ensuring that carers in their local area are aware of their rights to receive a carer's assessment, and all carers receive an assessment to address their support needs. This can include working with the NHS to improve early identification of carers and putting in place a formal fast-track process for the delivery of carers' assessments for those with severe, progressive conditions such as MND.
- Local authorities in England and Wales, and Health and Social Care Trusts in Northern Ireland, should commit to using and implement Carers UK's best practice guide on carers' assessments.
- Local authorities in England and Wales, and Health and Social Care Trusts in Northern Ireland, should make available a standard offer of carer wellbeing support, with built in flexibility, to ensure carers can take regular breaks to prioritise their health and wellbeing.

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What MND Association is doing

- Engaging with local councillors and other local decision makers, in partnership with our Campaign Volunteers, to raise awareness of the importance of carers' assessments.
- Influencing national policy through consultations, campaigns, and meetings, either directly or through coalitions, on the experience of unpaid carers of people with MND.

Lobbying MPs and other parliamentary stakeholders and groups, ensuring that the experience of unpaid carers of people with MND remains high on government agendas.

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